Modeling Electronic Reporting Project for Cancer Registries

The National Program of Cancer Registries (NPCR) at the Centers for Disease Control and Prevention (CDC) Division of Cancer Prevention and Control (DCPC) Cancer Surveillance Branch (CSB) has initiated a Modeling Electronic Reporting Project (MERP) for Cancer Registries. NCPR leads this collaborative including the National Cancer Institute/Surveillance, Epidemiology and End Results (NCI/SEER), Virginia Department of Health Central Cancer Registry (VCR) and the Virginia Commonwealth University's Massey Cancer Center (VCU).

The purpose of this project is to position the cancer surveillance community to take advantage of the electronic health record by developing a model using the Unified Modeling Language (UML) to transmit data from the hospital's electronic health record and hospital database systems to both hospital and state cancer registries. This model will also provide a framework for state departments of health to utilize standards recommended by the Public Health Information Network[i]/National Electronic Disease Surveillance System (PHIN/NEDSS)[ii] and the Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT)[iii].

This project is in line with the Department of Health and Human Services (HHS) Secretary Tommy Thompson's "Decade of Health Information Technology" initiative that includes implementing the widespread adoption of electronic health records.

The initial focus is to model and pilot electronic data transmission within a large university health care system from internal hospital database systems to the hospital cancer registry and to the state cancer registry. Data will be acquired from internal hospital electronic data sources and linked directly to the hospital cancer registry and ultimately to the state cancer registry. As part of the modeling processes state/hospital registries and subject matter experts will work collaboratively with the investigators to gain consensus on the structure of the model.

This model in turn will serve as the foundation by which a larger group of subject matter experts throughout the nation come together to develop a national plan. This initiative will establish resource priorities to advance the goal of electronic reporting of cancer surveillance data. The primary purpose for the model is to provide proof of concept to assure that practical application of the model is feasible.

There are many advantages to having a national plan. The first is to provide an infrastructure where the limited resources available to cancer registries can be marshaled around an agreed upon set of national priorities. The second will allow cancer registries to advance toward the goal of obtaining the majority of

cancer data electronically, thus resulting in more complete, timely, and accurate cancer surveillance data.

Please contact cancerinfo@cdc.gov for additional information regarding MERP. In addition, please respond to this contact information if you or your organization desires to be placed on the list of perspective subject matter experts for this project.

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[i] PHIN is a cross cutting and unifying framework for monitoring data streams for early detection of public health issues and emergencies. PHIN is composed of five key components: detection and monitoring, data analysis, knowledge management, alerting, and response. Information on PHIN can be found on the internet at http://www.cdc.gov/phin/.

[ii] NEDSS is an initiative that promotes the use of electronic data and information system standards advancing the development of efficient, integrated, and interoperable surveillance systems at federal, state and local levels for all reportable diseases. It is a major component of the PHIN. Information on NEDSS can be found on the internet at http://www.cdc.gov/nedss/.

[iii] SNOMED Clinical Terms (SNOMED CT) is a dynamic, scientifically validated clinical health care terminology and infrastructure that makes health care knowledge more usable and accessible. Information on SNOMED CT can be found on the internet at http://www.snomed.org/snomedct/.